Twenty Years of Public Health Research: Inclusion of Lesbian, Gay, Bisexual, and Transgender Populations

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Objectives. This study determined to what extent lesbian, gay, bisexual, and transgender (LGBT) populations have been studied over the past 20 years of public health research.

Methods. From MEDLINE English-language articles on human subjects published between 1980 and 1999, I identified articles that included LGBT individuals. The abstracts were analyzed with a coding procedure that categorized the content by topic, sexual orientation, and race/ethnicity.

Results. LGBT issues were addressed by 3777 articles, or 0.1% of all Medline articles; 61% of the articles were disease-specific, and 85% omitted reference to race/ethnicity. Research unrelated to sexually transmitted diseases addressed lesbians and gay men with similar frequency, whereas bisexual persons were less frequently considered, and the least amount of research focused on transgender individuals.

Conclusions. Findings supported that LGBT issues have been neglected by public health research and that research unrelated to sexually transmitted diseases is lacking. (*Am J Public Health.* 2002;92:1125–1130)

Despite increased interest in lesbian, gay, bisexual, and transgender (LGBT) populations' health as a legitimate focus of scientific study, public health research has not been systematically reviewed to identify the extent to which LGBT issues have been addressed. Historically, public health researchers have not recognized LGBT persons as a population with distinct health issues outside a framework of sexual deviance or sexually transmitted diseases (STDs). Before the 1980s, most studies that addressed LGBT populations focused on the etiology of homosexuality[1] or on mental disorders because homosexuality was classified as such until 1973.[2–4] In the 1980s, a new virus, later known as HIV, was initially recognized to occur among gay men.[5,6] Research on HIV and AIDS incorporated measures of same-sex behaviors to assess "risk behaviors."[7,8] In the 1990s, influenced by social movement advocacy, debate arose over whether lesbians' risk factors for developing breast cancer might be higher compared with those of heterosexual women.[1,9]

This focus on diseases that are of relevance to LGBT individuals developed into the recognition that LGBT populations are diverse communities with disparate health concerns. Hence, a systematic review of LGBT research also must identify gaps in knowledge regarding diverse sectors of LGBT populations in relation to behaviors, race/ethnicity, and socioeconomic position. This review is crucial to inform adequately the goals set for LGBT health in documents such as *Healthy People 2010: Understanding and Improving Health*[10] and its companion document on LGBT health, which addresses these populations more fully.[11]

Documents that strive to identify solutions to LGBT populations' health concerns, such as *Healthy People 2010* and the 1999 Institute of Medicine report on lesbian health,[1] regularly point to the lack of representative, population-based data on LGBT individuals. In the absence of adequate data, LGBT research is frequently hindered by methodological issues, such as defining, measuring, and sampling of LGBT populations.[1,2] The lack of uniform definitions and measures for LGBT persons, such as behavior, identity, and desire,[12,13] and of different sampling strategies severely limits the generalizability of study results.[14] Recognizing that existing LGBT studies may suffer from these limitations, one might wonder how often researchers have actually been able to collect data on LGBT populations and publish the results. Accordingly, the objective of this study was to determine the extent to which LGBT issues have been addressed in public health research and the contexts in which LGBT populations have been studied over the last 20 years.

METHODS

The National Library of Medicine contains 3 822 822 citations of articles based on studies with human subjects and published in English between 1980 and 1999. The goal was to determine how many of these studies specified the inclusion of LGBT individuals. With the same restrictions, a MEDLINE keyword search for the years 1980 to 1999 was conducted on Ovid on January 19, 2001. "Gay," "lesbian," "bisexual," "sexual orientation," "sexual identity," "bisexuality," "homosexuality, male," "homosexuality, female," "transgender," "transsexual," "transvestite," "cross-dresser," and "hermaphrodite" were used as key words. The abstracts of articles that fulfilled these requirements were downloaded and their content analyzed with a 3-step coding procedure:

1. The first coding step distinguished between disease-specific and non-disease-specific articles. The abstracts' contents were then summarized into broad areas that described a cluster of research topics.
2. The second coding step determined whether the abstract mentioned lesbian, gay, bisexual, or transgender individuals.
3. The third coding step focused on the race/ethnicity of the study population. Socioeconomic position of the study population was not coded, because data on this variable typically were either missing or poorly delineated.

To maximize the available data, all types of studies were considered, with the exception of letters that commented on research previously published. The first level of coding distinguished between articles that focused on specific medical conditions and those that did not. All articles that related their content to a specific disease were coded as "disease focused," even if their subject matter was psychosocial rather than biomedical. The implication of this coding rule was that caregiving was coded as disease-specific if the investigation was in the context of taking care of people with HIV or AIDS. An article on the caregiving burden of LGBT persons was non-disease-specific if it was not investigated in the context of a specific disease.

Mental disorders listed in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV),*[15] were coded as disease-specific, with 1 exception. Diverging from the *DSM-IV* classification of "gender identity disorder," articles on transgender identity were coded as non-disease-specific research on identity rather than a mental disorder. Continued examination of the data, reevaluation of codes, and refinement of coding rules led to the development of themes or broad areas that grouped non-disease-specific studies into clusters of research topics.

The second level of coding on sexual orientation and transgender identity led to the exclusion of articles that did not mention LGBT individuals in their abstracts. Because no agreed-on measure of sexual orientation exists and researchers often do not define sexual orientation,[14] coding of sexual orientation was not limited to specific definitions such as behavior, identity, or desire. Similarly, "transgender" had been added only recently to the lesbian, gay, and bisexual terminology, and the definition of transgender identity is evolving.[2,16] Over the years, different terms have been used; therefore, abstracts that mentioned transsexuals, transvestites, cross-dressers, or hermaphrodites were coded as "transgender."

Other coding rules evolved empirically. Abstracts referring to homosexual persons or homosexuality were coded as "gay" and "lesbian." Those that mentioned sexual orientation without specifying gender were coded as "lesbian," "gay," "bisexual women," and "bisexual men." Gay patients were coded as "gay." Furthermore, articles in which LGBT populations were only marginally addressed were included. This rule led, for instance, to the inclusion of articles that focused on heterosexual women but mentioned bisexual men in the context of heterosexual women's sexual risk behavior.

Because many abstracts provided incomplete descriptions of the study population with respect to racial/ethnic categories, coding of race/ethnicity was limited to either "race omitted" or "race reported." Research mostly lacked a definition of race as a biological, socioeconomic, or sociocultural construct.[17] Thus, the code "race reported" was not restricted to a specific definition of race/ethnicity and did not distinguish between self-reported and observed race/ethnicity.

RESULTS

The search of the MEDLINE database generated 4537 citations published between 1980 and 1999, which represented 0.1% of all articles recorded in MEDLINE. From the initial 4537 citations, 760 were excluded on the basis of the following criteria: (1) an abstract was not available, despite extensive efforts by the author to locate and review articles at various libraries; (2) they were letters in response to previously published articles; and (3) abstracts did not mention LGBT populations. The remaining abstracts of 3777 articles (0.1% of MEDLINE articles) were suitable for analysis with the 3-step coding procedure.

Table 1 provides summary information on the 3 categories by which the 3777 articles were coded. The majority of articles—2285 (61%)—were coded as disease-specific. Most articles focused on gay men (80%), followed by bisexual men (39%). Lesbians, bisexual women, and transgender persons, as a group, were included in 46% of the articles. Most articles (85%) omitted the racial/ethnic background of LGBT individuals.

Table 2 lists the topics of the 3777 articles organized into broad research areas. The vast majority of the 2285 disease-specific articles focused on STDs, particularly HIV and AIDS. Disease-specific research also occurred in the broad areas mental disorders and cancer. Articles on mental disorders focused mostly on addiction, followed by various psychiatric disorders, including schizophrenia and bipolar and mood disorders. Fifteen articles on sexual dysfunction included erectile dysfunction, dyspareunia, and compulsive sexual behavior. A cluster of 36 articles focused on various cancers, whereas 23 articles covered various diseases, subdivided into 8 infectious and 15 noninfectious diseases.

The content analysis of 1492 non-disease-specific articles was summarized into 7 broad areas. Most articles addressed identity, sexual behavior, and desire of LGBT populations. These articles considered the development of LGBT identity, including sexual choices and behaviors, relationships, coming-out issues, and aging, as well as body image and physiology, including gender-related surgery. The second largest research area consisted of 312 articles that focused on the etiology of sexual orientation and transgender identity, including research on the sexual orientation of siblings and twins and comparisons of hormonal levels between LGBT individuals and heterosexual individuals. The 207 articles on the health care of LGBT persons addressed providers' attitudes and cultural competency; the

TABLE 1—Distribution of Articles That Considered Lesbian, Gay, Bisexual, and Transgender Populations (N = 3777), by Content, Sexual Orientation, and Race/Ethnicity

	n	%
Type of content		
Disease	2285	60.5
Nondisease	1492	39.5
Sexual orientation[a]		
Lesbian	1043	27.6
Gay	3027	80.1
Bisexual women	352	9.3
Bisexual men	1486	39.3
Transgender	346	9.2
Race/ethnicity		
Omitted	3212	85.0
Included	565	15.0

[a]More than 1 sexual orientation can be addressed in a single article. Therefore, the number of lesbian, gay, bisexual, and transgender articles adds up to more than 3777 and more than 100%.

TABLE 2—Articles That Considered Lesbian, Gay, Bisexual, and Transgender Populations, by Content Areas (N = 3777; 100%)

Disease-Specific Content Areas		Non-Disease-Specific Content Areas	
Sexually transmitted diseases	2108 (55.8%)	Identity, sexual behavior, or desire	490 (13.0%)
AIDS, including opportunistic infections	1958	Identity, including gender or sexual identity	245
Sexually transmitted diseases other than AIDS	150	Relationship	66
Mental disorders	118 (3.1%)	Sexual behavior	51
Addiction, alcohol or drug	53	Coming out	39
Mental illness, including personality disorder	32	Aging	21
Sexual dysfunction	15	Physiology and body image	68
Pedophilia	10	Etiology	312 (8.3%)
Eating disorder	8	Neuroscience or endocrinology	141
Cancer	36 (1.0%)	Genetics and birth order	94
Anal cancer	16	History of homosexuality	47
Breast cancer	6	Various etiologic theories	30
Cervical cancer	3	Health care	207 (5.5%)
Ovarian cancer	3	Provider attitudes or patient-provider	126
Kaposi sarcoma (not AIDS related)	2	Health needs and utilization	81
Squamous cell cancer	2	Family	87 (2.3%)
Unspecified cancer	2	Parenting	61
Sertoli cell tumor	1	Reproduction	26
Nephroblastoma	1	Attitudes	75 (2.0%)
Various diseases	23 (0.6%)	Measuring attitudes toward lesbian, gay, bisexual, and transgender populations	29
Infectious diseases	8	Attitudes in educational institutions	15
Viral or bacterial infections	3	Images or stereotypes of lesbian, gay, bisexual, and transgender persons	18
Fungal infection	1	Change in attitudes toward lesbian, gay, bisexual, and transgender persons	7
Gastrointestinal diseases	4	Attitudes held by lesbian, gay, bisexual, and transgender individuals	6
Noninfectious diseases	15	Risk factors	70 (1.9%)
Heart disease	3	Risky sexual behavior	26
Menstrual disorders	2	Risky health behaviors	15
Respiratory disease	2	Suicide	17
Immune disorders	2	Prostitution	8
Osteoporosis	1	Stress due to minority status	4
Diabetes	1	Violence	52 (1.4%)
Breast disease	1	Assault	20
Benign tumor	1	Sexual abuse	16
Ovarian disease	1	Domestic violence	13
Urethritis	1	Various forms of violence	3
		Miscellaneous topics	199 (5.3%)
		Arts, literature	62
		Rights, legal aspects	27
		Community and lesbian, gay, bisexual, and transgender culture	27
		Methodology	21
		Freudian theory	21
		Religion or church	15
		Gay and lesbian studies	6
		Conversion therapy	5
		Career	4
		Social network	2
		Caregiving	2
		Articles on singular topic	7

TABLE 3—Distribution of Articles That Considered Lesbian, Gay, Bisexual, and Transgender Populations, by Specific Content Areas, Year of Publication, and Sexual Orientation[a]

	1980–1984					1985–1989					1990–1994					1995–1999				
	L	G	BW	BM	T	L	G	BW	BM	T	L	G	BW	BM	T	L	G	BW	BM	T
Sexually transmitted disease	2	42	2	24	0	13	262	11	213	1	37	715	24	475	10	64	955	47	453	9
Mental disorder	7	15	0	2	4	5	15	2	5	0	19	21	2	9	2	25	28	7	11	2
Cancer	0	0	0	0	4	0	3	0	3	2	0	3	0	2	3	9	11	4	9	0
Identity	33	47	10	9	33	51	60	11	24	35	59	72	16	18	40	85	97	28	30	32
Etiology	16	19	4	5	25	19	19	3	4	32	34	44	16	15	30	70	93	31	31	39
Health care	11	11	1	1	1	21	18	3	2	2	52	38	11	11	4	86	72	46	42	7
Family	10	5	0	0	0	16	9	1	0	1	10	6	0	0	0	38	13	3	3	1
Attitudes	4	6	0	0	1	5	6	1	1	0	18	17	2	2	0	36	37	8	7	0
Risk factors	0	1	0	0	1	1	9	0	2	4	6	17	4	8	0	17	34	9	13	3
Violence	0	1	0	0	0	2	4	0	0	0	11	14	3	5	1	19	26	7	8	0

Note. L = lesbian; G = gay; BW = bisexual women; BM = bisexual men; T = transgender.
[a]More than 1 sexual orientation can be addressed in a single article. Therefore, the number of lesbian, gay, bisexual, and transgender articles adds up to more than 3777.

patient–provider relationship; health needs of LGBT individuals; and their experiences with the delivery of health services. Family issues included parenting of and by LGBT individuals; alternative insemination; and adoption. "Attitudes" as a topic included measuring attitudes toward LGBT populations; attitudes in educational institutions; images and stereotypes of LGBT individuals; identification of people as LGBT; change in attitudes toward LGBT persons; and attitudes held by LGBT persons. Seventy articles focused on various risk factors, including risky sexual behaviors such as the lack of condom use. "Risky health behaviors" included research on smoking. Suicide, prostitution, and stress due to minority status among LGBT people are other topics among the category "risk factors." "Violence" was another area of research, including hate crimes, rape, incest, and domestic violence; 52 articles addressed violence.

Table 3 provides more detail on the 10 content areas of research, separating them by sexual orientation and years of publication. Although the number of articles in all areas increased with time, articles on STDs showed the biggest increase and focused predominantly on gay and bisexual men. Initially, research on mental disorders and cancer focused more often on gay men than on lesbians, but both were addressed with somewhat equal frequency in the 1990s. Among non-disease-focused articles, lesbian, gay, and transgender individuals were addressed in articles on identity and etiology more frequently than bisexual persons were. Research on health care focused predominantly on lesbians and gay men and less on bisexual and transgender persons. Family is the only content area that addressed lesbians more frequently than any other group. Research on attitudes, risk factors, and violence tended to focus more frequently on lesbians and gay men than on bisexual and transgender persons.

Table 4 presents all articles by sexual orientation and years of publication. It indicates differences in the proportion of research on each group and also after the exclusion of 2108 articles on STDs that focused predominantly on gay and bisexual men, as presented in Table 3. Comparisons of each group's proportion of articles between the first 5 years (1980–1984) and the last 5 years (1995–1999) of the study show the change in research attention on each group. The proportion of articles on lesbians and on transgender persons decreased by 5% and 22%, respectively. In contrast, the proportion of articles on gay men increased by 25%, on bisexual men increased by 20%, and on bisexual women increased by 5%. After research on STDs was excluded, the largest gain in research attention was among lesbians; articles on lesbians increased by 20%. Research attention on gay men, on bisexual women, and on bisexual men increased by 16%, 15%, and 15%, respectively, whereas research attention on transgender persons decreased by 21%.

The same calculations were performed with regard to race/ethnicity (data not shown). Between 1980 and 1984, 20 (7.8%) of 256 articles specified race/ethnicity, and between 1995 and 1999, 274 (16.1%) of 1707 articles specified LGBT persons' race/ethnicity. After articles on STDs were excluded, 16 (7.7%) of 207 articles specified race/ethnicity between 1980 and 1984, and 74 (10.4%) of 709 articles did so between 1995 and 1999. Thus, reporting of study subjects' race/ethnicity between the first 5 years (1980–1984) and the last 5 years (1995–1999) increased by a factor of 2, whereas reporting of race/ethnicity increased by only a factor of 1.3 among articles on non-STD-related topics. Therefore, the increase in recognition of subjects' race/ethnicity was driven mostly by STD-focused research.

DISCUSSION

LGBT persons are estimated to constitute between 1% and 10% of the total population.[12] Only 3777 articles, the equivalent of 0.1% of the MEDLINE database, focused on LGBT individuals over the past 20 years. This indicates that public health research neglected these populations and that LGBT persons are underrepresented as explicit research subjects.

TABLE 4—Distribution of Articles That Considered Lesbian, Gay, Bisexual, and Transgender Populations, by Sexual Orientation and Years of Publication[a]

	1980–1984 n (%)	1985–1989 n (%)	1990–1994 n (%)	1995–1999 n (%)	Total All Years N (%)
Lesbian	88 (34.4)	148 (25.2)	301 (24.6)	506 (29.6)	1043 (27.6)
Gay	152 (59.4)	419 (71.3)	1012 (82.5)	1444 (84.6)	3027 (80.1)
Bisexual women	18 (7.0)	38 (6.5)	90 (7.3)	206 (12.1)	352 (9.3)
Bisexual men	43 (16.8)	263 (44.7)	557 (45.4)	623 (36.5)	1486 (39.3)
Transgender	71 (27.7)	82 (13.9)	92 (7.5)	101 (5.9)	346 (9.2)
Total	256 (100)	588 (100)	1226 (100)	1707 (100)	3777 (100)
After exclusion of 2108 articles on sexually transmitted diseases					
Lesbian	86 (41.5)	135 (45.6)	264 (57.8)	442 (62.3)	927 (55.5)
Gay	110 (53.1)	157 (53.0)	297 (65.0)	489 (69.0)	1059 (63.5)
Bisexual women	16 (7.7)	27 (9.1)	66 (14.4)	159 (22.4)	265 (15.9)
Bisexual men	19 (9.2)	50 (16.9)	82 (17.9)	171 (24.1)	324 (19.4)
Transgender	71 (34.3)	81 (27.4)	82 (17.9)	92 (13.0)	326 (19.5)
Total	207 (100)	296 (100)	457 (100)	709 (100)	1669 (100)

[a]More than 1 sexual orientation can be addressed in a single article. Therefore, the number and percentage of lesbian, gay, bisexual, and transgender articles add up to more than the total.

The classification of articles by topic showed that 56% of the research on LGBT persons was disease-specific in the context of STDs. In particular, 52% of the research was disease-specific in the context of HIV or AIDS. Subsequently, the coding of articles by sexual orientation appears to indicate a gender gap, in that most articles focused on gay and bisexual men (80% and 39%, respectively). After the exclusion of STD-focused articles, this gender gap was greatly reduced.

Emerging in the 1980s, AIDS brought visibility to LGBT persons as a population with specific health concerns. One would expect that thereafter LGBT health concerns other than STDs would be examined. For example, some evidence suggests that LGBT individuals have a higher prevalence of known risk factors for heart disease,[1,2] the leading cause of mortality in the United States.[10] Behavior changes are targeted as primary prevention of heart disease in the general population.[10] Without public health research that explores heart-healthy lifestyle interventions in the context of sexual orientation and transgender identity, cardiovascular risk factors may not be reduced among LGBT persons.

It is unknown how many researchers attempted to move the focus of LGBT research to non-STD-related research topics, but funding was 1 major barrier that prevented a broadening of LGBT health research. A review of lesbian-, gay-, and bisexual-related National Institutes of Health funding indicated that, since 1982, $20 million annually was spent on HIV-focused research, compared with an average of $532 000 annually between 1974 and 1992 on lesbian, gay, and bisexual research unrelated to HIV.[18]

In the 1990s, the LGBT communities publicized AIDS and breast cancer as 2 major health threats to LGBT populations.[9] However, the review of the MEDLINE database did not reflect such notoriety, because only 6 articles on breast cancer were found—fewer than expected, considering the attention on breast cancer by LGBT communities and the national media. Without restricting MEDLINE to LGBT persons, using only "breast cancer" as a key word, breast cancer citations indexed in MEDLINE more than doubled from the 1980s to the 1990s—from 10 258 to 26 554 articles—which coincided with an increase in funding for breast cancer research in the 1990s.[19] Yet the expansion of breast cancer research neglected lesbians and bisexual women. Requiring the inclusion—or at least a justification of the exclusion—of sexual orientation and transgender identity, as the National Institutes of Health's Revitalization Act mandated for women and minorities,[20–22] would raise researchers' awareness and may be necessary to remedy the underrepresentation of LGBT populations in research.

The lack of knowledge about health problems of LGBT persons is further compounded with regard to race/ethnicity: 85% of the studies did not report race/ethnicity. Race/ethnicity has been shown to affect incidence, likelihood of survival, and mortality rates of many health problems. The omission of race/ethnicity is an important shortcoming within LGBT research because dual minority status—sexual and racial/ethnic—affects illness, health needs, and behaviors.

In addition, the duality of socioeconomic and LGBT status affects health and mediates its perceptions. The reviewed LGBT population–related abstracts provided only sparse, inconsistent information that did not allow even a basic coding of abstracts as reporting vs not reporting socioeconomic position. This lack of complete, uniform data is a major limitation of this review but is consistent with public health data, which mostly lack conceptually valid measures of socioeconomic status.[23,24] Another limitation of this analysis is its restriction to abstracts rather than articles to handle the sheer volume of studies. Some abstracts could potentially misrepresent the content of studies, but publishers generally urge authors to write abstracts that summarize their studies comprehensively, which made the coding of abstracts a reasonable approach. Another study limitation is the restriction to MEDLINE. Several journals that either exclusively or frequently focus on LGBT health are excluded from the MEDLINE database, suggesting the possibility that this review represents LGBT health only as reflected in 1 mainstream database and not the state of LGBT health research.

The finding that most LGBT research is related to STDs raises questions about the framework of lesbian-, gay-, bisexual-, and transgender-related public health research and points to the dominance of a biomedical paradigm that narrowly understands LGBT health in relation to sexual behavior. This reduction of LGBT individuals to their "different" sexuality needs to be expanded to include the recognition of sexual orientation and transgender identity as cultural and social

categories that shape all health experiences. A new framework that incorporates social and cultural categories will advance public health knowledge and research practice related to LGBT populations and will encompass the racial/ethnic and socioeconomic diversity of LGBT populations as well. ■

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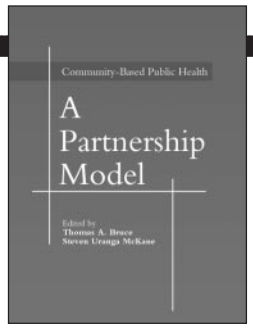

Community-Based Public Health:

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